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# School for Social Care Research

## Research with black and minority ethnic people using social care services

Tom Vickers, Gary Craig and  
Karl Atkin

## Methods Review 11

Improving the evidence base for  
adult social care practice



# The School for Social Care Research

The School for Social Care Research is a partnership between the London School of Economics and Political Science, King's College London and the Universities of Kent, Manchester and York, and is part of the National Institute for Health Research (NIHR) <http://www.nihr.ac.uk/>.

The School was set up by the NIHR to develop and improve the evidence base for adult social care practice in England. It conducts and commissions high-quality research.

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## Structured observational research in services for people with learning disabilities

### ABSTRACT

This review addresses research methods with Black and Minority Ethnic (BME) people using adult social care and support in England. During the last decade there have been considerable changes in how ethnicity is understood. Among these are exciting developments in research sensitive to ethnicity and the further development of anti-racist policy, practice and outcomes in social care. The review summarises these developments and offers practical advice on applying their lessons. Material from other disciplines including health and other disciplines is also drawn on for methodological advances relevant to social care research. The review is designed to be useful not only for researchers who are new to social care (and health care in particular) and hoping to learn more about this important topic, but to seasoned researchers, social care practitioners and students as well.

### RECOMMENDATIONS FOR RESEARCH ON ADULT SOCIAL CARE PRACTICE

- Social and health care need to adjust to a rapidly changing field, in which ideas about ethnic diversity are sensitive to time and place.
- To succeed, such research needs to avoid cultural determinism, when presenting collective responses, while simultaneously also avoiding idiosyncratic, subjective and potentially misleading guidance: these tend to make any efforts at generalisation impossible. This calls for greater sensitivity to the subtleties with which participants use cultural values and norms to give meaning to their experience.
- We suggest culturally competent research needs to engage more with the contingency of individual experience, particularly since the priorities of any individual might not be the same as those assumed by policy and practice. In support of this, understanding and engaging with ethnic diversity should be seen as integral to the general and core training of health and social care professionals, rather than as an ad hoc and add-on 'competence' to be achieved through brief training sessions. Such training should also help practitioners and researchers understand how their own judgements, values and assumptions impact on the patient. This will hopefully improve confidence when working in multi-cultural settings, without assuming there is one 'right' approach.
- Engaging with cultural, religious and ethnic diversity, while challenging stereotypes, should enable practitioners to raise meaningful questions within the context of providing care in an increasingly multi-cultural or super-diverse society. This would more appropriately reflect the complexity of people's lives, without relying on essentialised perceptions of particular cultural or religious groups.

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**KEYWORDS**

Black and ethnic minority, cultural diversity, culturally competent research, institutional racism, social justice, evidence-based practice.

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## INTRODUCTION AND CONTEXT

This review addresses research methods with Black and Minority Ethnic (BME) people using (in its broadest terms) adult social care and support in England. During the last decade there have been considerable changes in how ethnicity is understood. Among these are exciting developments in research sensitive to ethnicity and the further development of anti-racist policy, practice and outcomes in social care. Key objectives for this review included:

- summarising the underlying methods of previous research;
- describing those methods, what contributions they have made, and their limitations;
- reflecting on their use in social care practice studies; and
- making recommendations for whether and how these approaches might be more widely or rigorously employed.

The review is designed to be useful not only for researchers who are new to social care and hoping to learn more about this important topic but to seasoned researchers, social care practitioners and students as well.

Following a brief discussion of ethnicity and the context for research with BME people using social care, the review considers key steps in the research process, before drawing out conclusions.

The review took an integrative approach, with a search conducted primarily through online databases including Web of Knowledge and Social Care Online, specialist websites (listed in the 'Web Resources' Appendix) and wider searches; it was not a systematic review. An invitation for material to contribute to the review was circulated via online networks of researchers including the MINORITY-ETHNIC-HEALTH, SOCIAL-POLICY and RACE-ETHNICITY-CRIMINOLOGY academic Jiscmail lists and other networks. The authors consulted researchers during the course of the review, at the NIHR School for Social Care Research annual conference (2010), at a workshop organised by the Ethnicity Training Network and the Department of Health at the University of Leeds, at a seminar on 'Special Issues in Sampling Ethnic Minorities and Migrants' at the Royal Statistical Society, and at a workshop on 'Exploring Ethnic Diversity in UK Social Research' at the London Metropolitan University. These events themselves indicate that there is much interest in this topic among the research community.

Although this review has a social care focus, we draw at times on health and other research to illustrate certain points. Social care research can always learn from other fields, including children's services, education and housing.

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### Defining ethnicity/ies

When considering ethnicity in research it is helpful to be clear about its meaning and classifications or categories. Ethnicity can embody shifting and complex combinations of language, religion, faith, culture, ancestry, nationality, histories of migration and a shared heritage (Ahmad *et al.* 2002). These generate complex relationships, occurring in time and space, negotiated according to how the different aspects of ethnic identity support, sustain, reinforce and contradict each other. Ethnic identity may be a political symbol, defining not only exclusion by a powerful majority but also a source of pride and belonging for the minority (Parekh 2006). This enables minority ethnic populations to celebrate their difference, create a positive identity as a basis for collective mobilisation against forms of oppression on grounds of ethnicity, and to make legitimate demands on the policy and political processes (Anderson 2006; Craig *et al.* 2011). Like Salway *et al.* (2011), we employ the term 'ethnicity' loosely, but recognise the varied meanings that researchers and practitioners attach to it, in addition to lay (including user and carer) understandings, many of which include cultural, socio-political and/or genealogical dimensions. Social care has been an area where the term 'Black and minority ethnic' (BME) is often used and we continue this tradition here, noting however that this too may have different meanings.

People's identity, like their experiences of social care, will be influenced by their age, gender and socio-economic position, as well as by how others respond to these dimensions. The key is to understand when ethnicity makes a difference and when it does not. Ethnic identity is not fixed or predefined, but will have different meanings both for different people and for the same individual in different situations. Equally, expressing one aspect of identity at expense of another rarely reflects the way people live their lives and that many people now live comfortably with multiple identities. The theoretical and empirical implications of such approaches are beginning to find their way into mainstream research, policy and practice.

### Black and Ethnic Minority (BME) people using social care services

England is a diverse society in which socio-economic (and ethnic) inequalities in life chances and living standards show few signs of narrowing (Hills 2009). Inequalities and concentrations of disadvantage are associated with membership of particular minority ethnic groups and socio-economic status (class), and with employment/unemployment, general health and long-term limiting illness or disability and access to welfare services more generally (see Salway *et al.* 2007). Relative disadvantage suggests high levels of need for care and support, yet historically social care provision and research have fared poorly in understanding, responding to, or even investigating these needs. Much of the early work to change this was led by Black and disabled organisations themselves (e.g. Confederation of Indian Organisations 1987; GLAD 1991).



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### Progress and future directions

In some areas progress is being made in understanding difference and complexity in ethnic minority people's experiences of social care (see for example, Banks *et al.* 2006; Kalra 2006; Jayaweera *et al.* 2007; Manthorpe *et al.* 2009; Moriarty *et al.* 2011).

Researchers such as Rai and Withey (2006) have also demonstrated the potential for well-designed local studies to provide valuable information on ethnicity and disadvantage, to inform action for change. There has also been important service user-led research, such as that undertaken by BME mental health survivors (e.g. Kalathil 2008). Yet research has not made much impact on policy, practice and outcomes – which may reflect how research is funded, conducted and publicised. In light of this, this review aims to contribute to the quality of responses to ethnic diversity in research, by drawing together examples of good practice and common pitfalls, and to offer an accessible resource to people carrying out social care research outside an ethnic minority 'specialism' who want to improve their consideration of ethnicity in their own social care research and thus the impact of their research on practice.

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### KEY ISSUES

#### Ethics

Particular questions of research ethics arise where findings may have implications for members of marginal, disempowered or stigmatised groups (see Temple and Moran 2006, for a wide-ranging discussion of research with vulnerable populations and focused guidelines on research with refugees). The nature of research on ethnicity, and in particular its potential to contribute to *reification* – imputing a static and concrete existence to ethnic groups – and *essentialisation* – ascribing ethnicity a fundamental and causal role within individuals, means that we need to consider the impact of research not only on direct participants, but the potential for ‘group harm’, and negative consequences for those with no direct involvement in the research, who have had no opportunity to contribute and who have not given their consent. Salway *et al.* (2009b) point to the way in which

Untheorised or insensitive inclusion of data on ethnic groups can lead to negative consequences including: the creation/perpetuation of damaging stereotypes; exaggeration of differences between “groups”; and the production of culturalist explanations that ignore socioeconomic and political factors (p.3).

Such considerations need to be included at each stage of the research process, and measures taken to avoid discussions of ethnicity which may have essentialising, stigmatising or otherwise damaging consequences for the experience of or outcomes for BME groups. Describing experiences, without any context, is problematic and may lead to misunderstanding of minority populations’ experiences, to the extent that we never quite know how much or whether they are the same as or different from those of the general population. Bowling (2009), for example, has pointed to ways in which ‘active ageing’ may mean different things to different groups by ethnicity.

#### Ethics in social research with BME groups

The risk of harm to participants may be heightened in research by the potential lack of understanding of what would cause or constitute harm for participants with cultural differences from researchers, whether psychologically, socially or politically. For example, there is the relatively straightforward potential of different norms of demonstrating emotional distress, which may mean that a point may be passed at which a researcher with greater understanding would have discussed with the participant whether to stop the interview or signpost them to other sources of support (Fontes 1997). Issues of ‘sensitivity’ arising from perceived threat may be strongly culturally influenced. Elam and Fenton (2003) provide a useful introduction to general issues in dealing with sensitivity in research, particularly with ethnic minority populations, including ethics, involvement of target communities, ‘ethnic matching’ and dissemination and the media. Safety, trust and respect are defining features of positive practice relationships (Newbigging *et al.* 2007).

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These may apply in research, with being given a choice of interviewer one way to increase participants' power and confidence in research relationships.

#### Service user, carer and practitioner involvement

Where possible, members of target populations should be involved in the overall design of the research, improving accountability, practical relevance and verifiability. Researchers need to consult with local communities and marginalised groups about the types of research they should be doing, and how this work should be done. The very significant role played by members of ethnic minorities in the UK as carers and care workers should not be overlooked. Frequently, they are important sources of knowledge and understanding, with potential as both practitioner-researchers and research partners with other researchers.

There is also a need to work with practitioners to reflect the realities of their working practices and organisational contexts, rather than 'telling' them what to do by providing abstract solutions. This is important given the potential political sensitivities of working with diverse populations, where practitioners are often criticised for their actions but not offered alternative workable approaches. In research with disabled refugees and asylum-seekers, Roberts and Harris (2002) consulted a panel of professionals and representatives of sponsoring bodies, alongside a separate consultative group of refugees and asylum-seekers. Gonzalez *et al.* (2008) established a community research project to investigate interactions between BME people aged 50 and over and service providers in relation to mental well-being and mental health problems in Worcestershire and used community engagement techniques to explore these potentially sensitive subjects.

#### Translation and interpretation

Research, like social care practice, is wary of using family members as translators because they may not use language in the way that the researcher intends and there is the potential to omit, add, condense or substitute information (for discussion of dynamics of informal translation within families see Mir and Tovey 2003; Atkin *et al.* 2009). However, using interpreters may undermine the richness of qualitative data unless great care is taken in preparation and training. Detailed accounts are available of creative strategies developed in work with particular populations, many of which emphasise the importance of pilot studies and built-in measures for verification in order to develop research tools and practices tailored to the specific research question and population. For example, in a study with Eastern and Central European migrants, Ruhs *et al.* (2006) report their experiences of the importance of extensive discussion of translated research instruments between principal researchers and assistants which, in addition to enhancing comparability of results, also had the benefit of giving interviewers greater understanding of the intention behind questions and a sense of ownership of the research. In another study, testing of research instruments identified that, despite the development of a translated version of the survey, in practice interviewers generally preferred to use the original English version in interviews but to conduct discussions in Somali, and suggested that use of the written

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Somali version would lose the flexibility and nuances of a predominantly oral language (for discussion of a variety of data collection tools developed as alternative to written questionnaires see Johnson *et al.* 2009; Lloyd *et al.* 2008b). The availability of an informed range of choices for participants seems critical, as is the need to ensure conceptual equivalence rather than literal meaning, when translating (Atkin and Chattoo 2006).

While the cost implications of best practice in translating research tools often lead to compromises, such as contracting out translation of questionnaires (McManus *et al.* 2006), active participation of the research team in translation may have scientific and ethical benefits. These may range from involvement of members of the target group in the research design, to ensuring a sufficiently shared understanding as a basis for genuinely informed consent, to interpretation of data, accessible dissemination products and implementation of findings.

#### Informed consent in multi-lingual research

Lloyd *et al.* (2008a) report, in some detail, how they developed a process to obtain informed consent from individuals whose main language does not have an agreed written form, in this case Mirpuri and Sylheti. This was through the use of audio recordings of rigorous translations of the standardised participant information sheet in a study of people with diabetes in Birmingham. These were offered alongside written versions in several languages read out to participants by family members, with verbal confirmation of understanding and consent also recorded by tape. An important point from this study, which has wide applicability, is the creation of a range of ways through which participants could access information and convey consent, maintaining consistency in levels of understanding, engagement and consent through a diversity of methods.

#### Conceptual translation

The need for research to be 'culturally competent' (Papadopoulos 2006) is reinforced by the need for meaning to be accurately conveyed from participants to researchers, for participants' wider contexts to be understood, and for researchers to avoid unintentionally causing harm or offence to participants or other members of the target group. Praat *et al.* (2005) found various effects of culture on the role and treatment of disabled people by their family members, while Bignall and Butt (2000) identified a significant role played by religion in the self-definitions of 'independence' for some BME disabled people. The potential for such effects needs to be accounted for in assessing individuals' outcomes and measures. Translation of research instruments therefore also needs to consider psychometric equivalence, or cultural as well as linguistic translation, as meanings of the same events, activities or practices, used for example in scales to measure depression, may differ with culture as well as language (Oakley 2006). Mallinson and Popay (2007) have outlined practical approaches to 'culturally neutral' assessments of mental distress and Bhopal *et al.* (2004) have described approaches to cross-cultural adaptation of surveys. Another approach is to use techniques focused on inviting

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participants to formulate their own frameworks of understanding, such as the qualitative 'photovoice' techniques based on the work of Wang and Burris (1997), where participants take photographs and use them to generate discussion of their experiences.

#### Funding, commissioning and publishing

Decisions made in the funding, commissioning and publishing or dissemination of research carry a powerful influence over its consideration of ethnicity, yet members of ethnic minorities have often been excluded from participating in these activities, perhaps more so than any other stage. Barley and Salway (2009) surveyed a range of government social research departments and private research organisations about their procedures and competency in dealing with questions of race and ethnicity, finding a patchy picture in responses.

#### Making better use of available resources

In practice, researchers have to make the best use of funding and resources which sometimes do not allow for extensive consideration of ethnicity. Atkin and Chattoo (2006) argue for the importance of a critical approach, focusing resources where they can contribute the most and questioning whether further primary research is the best way to proceed. Katbamna and Matthews' (2007) profile of BME older people in England provides a detailed analysis of how to use existing data (in this case the 2001 Census) to great effect, rather than undertaking primary research.

Rai-Atkins *et al.* (2002) provide a useful example of how one project responded to a situation of limited funding and extensive ethnic diversity, by recruiting a lead project officer with proficiency in at least one language whose speakers had generally low levels of proficiency in English, and complementing this with a diverse advisory group and several 'project consultants', the latter drawn from other target groups, employed on a sessional basis.

#### Peer review

The peer-review process used in both commissioning and publishing research means that the quality of consideration of ethnicity relies heavily on the expertise of reviewers who may not be specialists in this area. Salway *et al.* (2009a) worked with journals to develop guidance 'checklists' for authors and reviewers to use as a prompt for considering particular issues relating to 'race' and ethnicity. Some editors did not want to overburden reviewers with further guidance, and even some journals which had offered guidance documents on ethnicity for several years found many regular reviewers were unaware of their existence. Five journals\* approached agreed to develop such checklists, and now offer them on their websites.

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\* *Anthropology in Action, Diversity in Health and Care, Ethnicity and Health, the Journal of Social Policy and Social Policy and Society.*

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#### Legal requirements

It is worth noting that, as with the Race Relations Amendment Act (2000), the Equalities Act (2010) places a statutory responsibility on researchers and those employing them to engage with ethnic diversity. For example, research should not exclude ethnic minority populations by restricting its focus to people who, for example, speak English; or, more generally, fail to recruit ethnically diverse samples, simply because researchers lack experience of working in multi-cultural contexts.

#### Research design

The design of research that is sensitive to ethnic difference and disadvantage will necessarily include the definition of ethnicity as a concept, and particular ethnic categories as relevant to the research. One review found that research on services for ethnic minorities generally lacked a comparative component, making it difficult to ascertain whether other service users experienced similar or different problems (Chahal 2004). It is therefore important to build in considerations of ethnicity alongside other factors, and the potential for comparisons, from the design stage. A recent study by Lawrence *et al.* (2011), for example, looked at the subjective reality of living with dementia from the perspectives of people with dementia within the three largest ethnic groups in the United Kingdom (White, Black Caribbean, and South Asian). By including a White group they were better able to think about ways in which culture seemed to affect people's perceptions of having a valued life.

#### Ethnicity in context

Atkin and Chattoo (2006) point to the need to locate analysis of ethnicity in the broader literature, to enable its consideration alongside other aspects of difference and assess when ethnicity is likely to be a key factor; For example, Badger *et al.* (2009) undertook a literature review of the role of ethnicity in end-of-life care in care homes for older people.

In research on ethnicity and degree attainment, Broecke and Nicholls (2007) reported the use of filters in constructing their target population, as an approach to controlling for factors other than ethnicity, although such approaches should be taken with caution, avoiding 'controlling out' factors which may themselves be associated with ethnic differences, such as pre-university attainment of qualifications. Ellison (2005) suggests that considerations of ethnicity are strengthened where researchers reflect on and clearly explain whether they are using 'race' or ethnicity as a proxy for another variable or composite of other variables, offering a decision tree as a simplified aid to considering whether measurement of 'race' or ethnicity is appropriate in particular cases. Central to this is the exploration of the context in which ethnic categories are constructed. Preliminary analyses of the Millennium Cohort Study suggest that *ethnicity matters* in determining outcomes, but that it is important to consider inter- and intra-group differences. The influence of specific factors needs to be considered, such as migrant



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status, English fluency, educational qualifications, and access to money and resources, which can sometimes be difficult to separate.

Patterns of disadvantage are produced alongside the construction of ethnic categories, and this poses a problem for research which sets out with already-established categories, threatening to lead research into 'the dead-end of cultural difference', leaping from evidence of ethnic inequalities to assumptions of cultural causes, potentially being seriously misleading (Kalra 2006). For example, a number of outcomes specific to members of Traveller communities in England can be traced to their increasingly limited accommodation opportunities (Brown and Scullion 2010).

#### Sampling

Sampling of ethnic minority populations often faces the challenge that there is no complete sampling frame including ethnicity data from which to draw a sample. This may be particularly pronounced for 'hidden populations', such as refugees, for whom researchers lack even basic overall data, making the construction of a robust sampling frame impossible and therefore limiting the utility of purely quantitative research methods (Esterhuizen 2004). Researchers have made use of specific surveys such as Ethnibus and have built on Office for National Statistics (ONS) Omnibus Surveys (<http://www.statistics.gov.uk>) by adding questions to this (for example see Bowling 2009).

Where a simple comparison of some question between ethnic groups is desired, it may be useful to use purposive sampling with an equal target number from each ethnic group (for example see Mallinson and Popay 2007). Other questions may require more sophisticated approaches to sampling. This may be complex when ethnicity is not a central concern of the research, but where researchers want to build into their sample an understanding of ethnic influences or differences in their findings, or ensure that findings are representative of ethnically diverse populations. In research on educational attainment, attempts to compare by ethnicity require consideration of what we are trying to achieve in sampling, and what factors of ethnicity should be included. Some studies – especially qualitative ones – offer little more than descriptive accounts because they provide accounts of one specific ethnic group, with limited attempts to contextualise this experience. One practical solution is to ensure sampling reflects a broad range of ethnic identities, or otherwise contextualise the research in the broader and more general literature.

Analytically, inclusion of more diverse samples has to have a point. It is possible to include greater ethnicity diversity in sampling, but researchers need to know how to make sense of the material and locate it within broader theoretical and empirical discussion. Researchers, therefore, need to reflect carefully on the analytical relevance of recruiting more ethnically diverse samples, thinking beforehand about what they are going to do with this material and the consequences for the study as a whole.

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### Booster samples

Sometimes, the potential to address complexity and difference within and between ethnic groups may be substantially increased by the use of 'booster samples'. This allows investigation of ethnic groups or sub-groups which make up a small percentage of the general population, and would therefore give an insufficient total number through standard random sampling. McManus *et al.* (2006) discuss, in some detail, strategies and limitations in constructing booster samples, including complex weighting of boosted samples for representative use alongside general population data. Nazroo *et al.* (2009) provide an example of booster samples for Irish, Black Caribbean, Indian, Bangladeshi and Chinese populations in the National Health Survey for England, whilst Plewis *et al.* (2004) give a detailed account of the sampling strategy used in the Millennium Cohort Survey. The latter includes discussion of the use of child benefit payments as the basis for selecting the sample, indicating groups that this excluded, such as asylum-seekers, ineligible for child benefit due to immigration status. In a recent overview of elder abuse and ethnicity, Manthorpe and Bowes (2010) outline the ways in which studies of this sensitive topic sought to access a variety of participants, such as going through voluntary and community groups. They were able to place this in the context of a survey that had not enlisted many BME older participants.

For areas which are thought to have higher concentrations of ethnic groups under consideration, door-to-door screening is often the preferred method of boosting a sample for a particular group. However, this relies on predictions of ethnic density for target groups in particular geographical areas, which have often been based on the previous Census, and may be outdated as they may not capture changing migration patterns, particularly since 2001. In areas thought to have lower concentrations of minorities, 'focused enumeration' has been used increasingly (Brown and Ritchie 1981) (this involves asking at a respondent at a main sample address about the eligibility of those living at addresses to the left and the right of them). While early findings from recent evaluations suggest that this may produce both a significantly lower yield than (very expensive) face-to-face screening, and significantly skewed samples, with a bias towards identifying 'visible' or longer-established groups and in particular South Asian groups, it is one way of boosting samples (Smith *et al.* 2010)

### Sampling dispersed and 'hidden' populations

Effective sampling of some ethnic categories requires entirely different strategies. Nazroo *et al.* (2005) suggest additional sampling measures to improve coverage of particular groups, including drawing a sample from existing surveys to boost the achieved sample of ethnicities which are often more widely dispersed, such as 'Chinese' and 'Mixed', or conducting parallel studies in order to cover groups such as Travellers which may require specific strategies not fitting with the design of the main study. Administrative data sources containing information on questions such as issuing of national insurance numbers or granting of citizenship or leave to remain can be combined together to indicate areas



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of higher density of a particular group for more effective sampling. For example, Brown and Scullion (2010) have listed several sources to help estimate a 'base population' of Traveller communities, although none of these offers a complete picture. Even when combined, such estimates are likely to exclude some, particularly those in 'bricks and mortar' private accommodation and those concealing their 'Traveller' identity for fear of harassment or other forms of discrimination (Brown and Scullion 2010). Craig *et al.* (2010) combined informal methods developed to map ethnic minority populations thought to have changed significantly since the last Census, combining administrative data with substantial 'detective work' in the form of networking, visits to relevant ethnic minority-run businesses and places of worship, and observation. As Lievesley's (2010) detailed analysis of population trends has identified, many areas are likely to see higher numbers of BME older people, not only areas that are generally identified as being centres of settlements.

#### Access, recruitment and consent

There are many accounts of research in which the marginal position of BME people creates obstacles to access and recruitment, leading to longer than anticipated time required for research to be completed (Salway *et al.* 2011). NBCWN (2008) suggest that groups commonly characterised as 'hard-to-reach' may be more accurately understood as 'easy-to-ignore', and that accessing ethnic minorities is not difficult, but rather a matter of assessing and committing the necessary time and resources. Many studies do manage to recruit ethnically diverse samples through processes of engagement with community and faith groups as well as bodies with responsibilities for statutory equal opportunities (Manthorpe *et al.* 2009). Brown and Scullion (2010) suggest a designation of 'hard to reach' may also reflect 'a lack of knowledge on behalf of the researcher about how, who, and where to contact certain groups or individuals, rather than an innate inclination for separateness of the group or individuals concerned'. Thus, what is ascribed to a fundamental characteristic of ethnic minority research subjects may actually be rooted in a deficit on the part of researchers. For example, Hussain-Gambles (2003) demonstrate how it is the assumptions of researchers conducting trials that are more likely to explain poor recruitment among ethnic minority populations, rather than the assumptions of ethnic minorities themselves.

#### Tailoring recruitment strategies

Participant recruitment must also consider the implications of specific approaches. This is because differential access of people from different ethnic groups to information, networks and services may have consequences for participation (Oakley 2006). McLean and Campbell (2003) report particular and potentially localised differences by ethnicity in recruitment, with the organisational links and perceived political relevance of the research appearing particularly important in recruiting among African-Caribbean populations, personal contacts and introductions most significant among Pakistani-Kashmiri, and financial incentives among white English respondents. This highlights the value of piloting

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recruitment strategies before large-scale implementation. Based on their experience of research with Traveller-Gypsy populations, Brown and Scullion (2010) suggest adopting diverse strategies to gain access to participants, including the most marginalised, involving 'opportunistic sampling' such as attending sites and events; 'snowballing', beginning with accessible contacts such as community workers, health visitors, or site managers; and personal contacts of Gypsy-Travellers trained and employed as 'Community Interviewers/researchers'. They also discuss some of the drawbacks and potential sample biases which these methods may create.

#### Barriers to access

Barriers to access for researchers exist in many cases. This may be due to growing perceptions that although BME communities have participated in research, they have seen very little benefit as a result (Culley *et al.* 2007; Brown and Scullion 2010). Hanley (2005) reports a diversity of views about research among ethnic minority populations. Some communities feel they have been 'over-researched' but seen little resultant change and are therefore demotivated from future participation. Other groups, such as 'new' groups of migrants or disabled ethnic minority people, may be excluded from research which aims to involve ethnic minority people but does not take account of diversity among and within ethnic minorities as well as between 'them' and the White majority (Hanley 2005). For numerically small ethnic groups, this may call for significantly higher levels of participation per person than for larger groups, and this differential burden on participant populations needs to be borne in mind by researchers in considering whether a particular piece of research or method is justifiable against the time, energy and intrusion required of participants.

Researchers need to consider how to respond creatively to such concerns, not merely to convince participants that a piece of research is worth contributing to, but to address how the research can be made of greater use to those it targets. While there are many examples of effective recruitment strategies for researchers to draw on (for example Ruhs *et al.* 2006; NBCWN 2008; Poudrier and Mac-Lean 2009), McLean and Campbell (2003) suggest that recruitment should be about more than simply increasing the total number of members of ethnic minority groups in the sample. They recommend making efforts to relate research to the values, interests and practices of potential participants in order to engage them in developing findings and searching for ways to apply them (see also Salway *et al.* 2011). Horowitz *et al.* (2009) report recruitment of minority populations using diverse initial contact points as part of a process of community-based participatory research, in which community members and representatives identified research priorities in partnership with academics, and were engaged and supported in carrying out research. The authors identify 'commitment of both community and academic partners to each other and to the research' as key to a project's success.

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#### Informed consent

In securing informed consent to participate in research, particular issues may arise in research with ethnic minority populations. For different groups these might include: culturally-influenced priorities assigned to verbal commitments as more meaningful than written; fear of identification and reporting to authorities if migrants with irregular status sign official-looking documents; perceived compulsion to participate, either as result of obedience to 'community leaders' and/or compliance with official institutions of the host country; or various forms of miscommunication (Culley *et al.* 2007; Johnson *et al.* 2009). It is more important than ever that researchers qualify commitments to confidentiality before obtaining consent, and ensure that these are fully understood.

#### Data collection

Data collection has received perhaps the most attention within research with ethnic minority populations, most commonly in discussions around matching interviewers to participants by spoken language proficiency and/or ethnicity, age or gender. While researcher-participant 'matching' is important to consider, it is not enough on its own, and may have drawbacks, as discussed below. If conditions are to be created for the collection of meaningful and valid data in a diverse society then ethnicity, language, culture and racism all need to be considered more broadly as possible factors influencing participant actions and responses, researcher behaviour, and the interactions between researchers, participants and the wider research setting which contribute to the production of data. Sharma *et al.* (2009) stress the importance of acknowledging the ethnic 'embodiment' of the researcher(s) as well as the researched in their relations to the research, participants and wider society. They suggest practical methods, such as reflective interviewing between co-researchers, and treating as potentially significant data the full range of researchers' responses to the research situation - emotional as well as intellectual – which may yield important insights into aspects of lived experience, including cultural and ethnic difference.

#### Sensitivity

Sensitivity around particular questions may influence what data are sought and how. For example, Aspinall and Chinouya (2008) suggest that individuals' migration route and status may be 'as significant as country of origin, ethnicity, religion, and language in shaping migrants' identities, their group allegiances, and social interactions', but that respondent sensitivities may sometimes make it impractical reliably to gather this information. Elam and Fenton (2003) provide a list of suggested strategies for dealing with sensitivity in data collection with ethnic minority populations, focusing on systematically increasing information and control for participants. Where research participants may have uncertain immigration status, there is a need for particular care in training of interviewers and anyone else with access to identifiable data so as not to divulge the immigration status of individual participants to anyone outside the research

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project, and to ensure that interviewers have a basic understanding of the background of British immigration law and regulations (Ruhs *et al.* 2006). This aspect of research with minorities is often overlooked in codes of ethics and safety.

#### **‘Community interviewers’ and ethnic matching**

Despite arguments for advantages in the quality of data, ‘ethnic matching’ of researchers with research participants as a panacea for effective research has been criticised on grounds which include its implicitly essentialist and homogenous view of ethnicity (Elam and Fenton 2003; Ruhs *et al.* 2006). Ethnic matching may prove a disadvantage where participants do not feel sufficiently assured by promises of confidentiality or where they would like to express counter-cultural views about topics such as religion or gender relations. The purposes and drawbacks of matching researchers and participants by ethnicity, language and other characteristics need to be considered carefully, not only in data collection but throughout the research process (Grewal and Ritchie 2006). There is a danger that uncritical assumptions that ethnic matching equals culturally competent research may distract from the need to develop researchers’ skills, experience and understanding in dealing with ethnicity. Approaches which have been found to be effective have included recruitment focused on skills and understanding, supplemented where necessary with training in both research techniques and the substantive issues under consideration, a degree of choice for participants as to which researcher they work with, and including people involved in data collection in the analysis stage (Elam and Fenton 2003; Culley *et al.* 2007). Edwards and Alexander (2010) have reported work with peer, community or lay researchers, that needed to address tensions between emancipation and democratisation of knowledge production, and an instrumentalist drive to use the trust and networks of peer researchers to access ‘hard-to-reach’ communities. They provided three case studies of how these questions were negotiated in their research (see also Bowes 1996, for reflections on tensions around racism and anti-racism in relations between researchers and participants in action research in Glasgow).

In research with migrants, refugees and asylum-seekers, there is a developing literature about the advantages of using community interviewers (for example Phillimore *et al.* 2008; Lewis *et al.* 2009; Scott *et al.* 2012).

#### **Analysis**

Wherever possible, considerations of ethnicity should be built in from the earliest stages of the research process; where it is only possible to introduce them at the analysis stage, this should be done with caution. Introducing considerations of ethnicity only ‘post hoc’ at the analysis stage, looking for ethnic difference based on diverse or nationally representative samples without addressing differences such as education, occupation and family income, carries the danger that findings due to difference of class or other factors may be given racialised explanations (Fontes 1997). A related danger is that an over-emphasis on ethnic differences may lead to the dismissal of serious problems within one

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section of the population on the basis that they are also prevalent in wider society (Salway *et al.* 2009b).

Some researchers have suggested that the validity of data analysis is considerably strengthened by the insights of members of target groups at this stage of the process, whether as employed co-researchers, advisors, or participants in 'community' discussions of anonymised data or initial findings (Rai-Atkins *et al.* 2002). For example, Vernon (2002) demonstrates the potential contribution by ethnic minority disabled people in understanding complex interrelations of religious and cultural practices, family life, definitions of independence, racism and disablism.

#### Measuring outcomes

Analysis of the results of interventions needs to be clear whether it is aiming to measure access, or outcomes, or both. A range of research has identified a serious lack of information on entitlements and services among ethnic minority people, even where there are no language barriers, with a particular lack of information among recent migrants (Chahal 2004; Newbigging and Lowe 2005; Craig *et al.* 2006; NBCWN 2008) when people are not even aware of what is available, let alone able to overcome any barriers to access. We perhaps also need greater sophistication in how we understand social care policy and its impact and engagement with BME people. The role of practitioners, however, is equally significant. Effective assessment of outcomes calls for attention to success in the terms defined by users and their supporters, as opposed to simply measuring them against the models of care and wellbeing held by policymakers, practitioners, or the dominant cultural norms of wider society (see Hepworth 2003, for an example of trialling self-assessment tools with carers of specific ethnic groups, enabling the identification of areas of applicability and areas needing amendment or translation). In terms of implications for research, policy and practice, issues of appropriateness and accessibility, therefore, remain inseparable, of equal importance in improving outcomes for BME populations, and represent a dynamic tension in practice.

#### Representing BME experiences

A more general problem of analysis (and interpretation) is how to represent the experience of ethnically diverse populations, without recourse to sweeping generalisations which can essentialise the experience. We mentioned above the importance of knowing when ethnicity makes a significant difference to a person's experience and when it does not. Uncontextualised and descriptive studies, which emerge when researchers know little about a subject, struggle to capture the subtle and nuanced experience of those being researched.

#### Presentation and dissemination

If research is to be accountable and of use to those it concerns, consideration needs to be given to how findings are presented and disseminated. Dissemination needs to consider

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how to translate findings into a range of languages and make summaries available in places where they can easily be accessed, such as community centres and faith-based buildings. Some researchers, such as the Social Services Research Group, make explicit reference to the need to budget for necessary measures to meet equal opportunities requirements in publicity and dissemination. Brown and Scullion (2010) note that making findings accessible to participant populations may require taking account of varying literacy levels and the nomadic nature of some communities, and suggest that useful forms of dissemination might include 'community reports, workshops, leaflets, audio reports and media coverage (both specialised and general)'. In addition to a written report, Roberts and Harris (2002) included information workshops, a 'workbook' for service providers, and an information poster informing disabled refugees and asylum-seekers of their rights and sources of support.

#### **Avoiding group harm in dissemination**

Dissemination of research which discusses ethnicity also needs to account for the role of the media, the presentation of ethnicity in research more generally, and that interpretation of publicly-available findings cannot always be controlled, making unintended contributions to racialised stigma. This may require strategies such as anonymisation of country groups, and reinforces the importance of participatory approaches to dissemination, building in accountability to those the research discusses (Elam and Fenton 2003). Gunaratnam (2001) responds to such questions of sensitivity and accountability by reflecting on the overall context of research situations, and advises avoiding decontextualised 'snippets' in dissemination. She suggests including researchers' questions in order to remind the reader that this is an interview situation and allowing a more critical engagement by the reader.



## CONCLUSION

In research, important dilemmas face those attempting to accommodate ethnic diversity, within the context of a multicultural society. Many of the problems raised here are longstanding, reflecting a deeper problem about how we can translate research evidence into policy and practice rather than constantly attempting to re-invent the wheel. All these issues become more rather than less significant as the UK moves towards becoming a super-diverse country where even hitherto 'White' towns may now accommodate people from as many as 100 different national origins (Craig *et al.* 2010; Fanshawe and Skrikandarajah 2010; Lievesley 2010), meaning far larger numbers of social care services can expect to have great diversity among their users (Manthorpe *et al.* 2010).

The better-understood processes of disadvantage and discrimination can sometimes mislead those who are familiar with current debates into thinking that there is little else to do. Our growing awareness, however, has not always equated with more responsive social care. The UK offers several examples of this. Empirical research has long discredited stereotypes of minority ethnic families who 'look after their own'. These ideas, however, still surface in the attitudes of some practitioners and policymakers. Essentialism, which has also long been discredited in academic circles, is beginning to re-emerge, as research, policy and practice slowly respond to the multicultural nature of society (Chattoo and Ahmad 2008). Debates about the complex nature of ethnic identity seem cast aside, if researchers, unfamiliar with such debates, apply idiosyncratic and poorly contextualised ideas of the meaning of ethnicity.

A focus on the fluid and contingent nature of ethnicity does not necessarily sit easily with the stark divisions and inequalities social researchers attempt to understand. Research needs simultaneously to account for ethnicity's shifting nature and the very real and concrete impact of racism on people's experiences and outcomes. This requires a turn away from culturalist explanations of inequality – in which differences in outcomes are seen as determined by cultural factors, and therefore the responsibility of disadvantaged groups themselves – towards an understanding of the ways in which aspects of ethnic identity are realised, politicised and given material force through the process of social negotiation and dynamic power relationships. To this extent, the concern of research is not to offer neat prescriptive cultural descriptions, purporting to explain and manage 'ethnicity', but a more general discussion which contextualises diversity and difference, without recourse to simplistic explanations and naive solutions, perpetuating disadvantage and discrimination.

At the same time, describing and documenting disadvantage creates a potential jeopardy. Constantly highlighting negative consequences of service provision may do little to advance thinking and practice, condemning everything while proposing nothing and creating a sense of inertia, making active engagement problematic. Policy and practice have not been particularly successful in translating evidence, outlining the process and outcomes of discrimination, into tangible improvements in social care services. As Taylor

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(1994) observed, to sustain multicultural societies, we need to develop 'the politics of difference' - in which there is a political commitment to ensuring diversity does not become the basis for inequality – rather than a narrow view of the 'politics of representation' – in which recognising difference becomes confused with responding narrowly to it.

At every stage of the research process, from commissioning to dissemination, we need to be alert to the ways in which a diversity of relationships – around 'race', culture, religion, language, nationality, class, gender, disability, life history, age, mental health, and sexuality – connect individuals, as part of groups, to wider contexts and processes up to an international level, in a two way, dialectical process. This is in addition to reflecting this in outcomes and a commitment to tackling disadvantage and discrimination. As Marx observed, we make our own history, but not in the circumstance of our choosing.



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References

- Ahmad WIU, Atkin K, Jones L (2002) 'Being deaf and being other things: South Asian deaf young people and identity negotiation.' *Social Science and Medicine*, 55, 10, 1757–1769.
- Anderson B (2006). *Imagined Communities*, Verso, London.
- Aspinall PJ, Chinouya M (2008) Is the standardised term 'Black African' useful in demographic and health research in the United Kingdom?, *Ethnicity and Health*, 13, 3, 183–202.
- Atkin K, Ali N, Chu CE (2009) The politics of difference? Providing a cancer genetics service in a culturally and linguistically diverse society, *Diversity in Health and Care*, 6, 3, 149–157.
- Atkin K, Chattoo S (2006) 'Approaches to conducting qualitative research in ethnically diverse populations.' in J Nazroo (ed.) *Methodological issues in research relating to black and minority ethnic groups: Publishing the evidence*, Taylor & Francis, London.
- Badger F, Pumphrey F, Clarke L, Clifford C, Gill P, Greenfield S, Knight Jackson A (2009) The role of ethnicity in end-of-life care in care homes for older people in the UK: a literature review, *Diversity in Health and Care*, 6, 1, 23–29.
- Banks L, Haynes P, Balloch S, Hill M (2006), *Changes in communal provision for adult social care 1991–2001*, Joseph Rowntree Foundation, York.
- Barley R, Salway S (2009) Social research for our multiethnic society: are UK researchers adequately trained and supported?, *Social Research Association Newsletter*, SRA, London.
- Bhopal R, Vettini A, Hunt S, Wiebe S. (2004). Review of prevalence data in, and evaluation of methods for cross-cultural adaptation of, UK surveys on tobacco and alcohol in ethnic minority groups, *British Medical Journal*, 328, 76–80.
- Bignall T, Butt J (2000) *Between ambition and achievement: Young black disabled people's views and experiences of independence and independent living*, Joseph Rowntree Foundation/Policy Press, Bristol.
- Bowes A (1996) Evaluating an Empowering Research Strategy: Reflections on Action-Research with South Asian Women, *Sociological Research Online*, 1, 1, <http://www.socresonline.org.uk/1/1/1.html>. Retrieved 23 February 2010.
- Bowling A (2009) Perceptions of active ageing in Britain: divergences between minority ethnic and whole population samples, *Age and Ageing*, 38, 6, 703–710.
- Broecke S and Nicholls T (2007) Ethnicity and Degree Attainment. Research Report RW92, Department for Education and Skills, London.
- Brown C, Ritchie J (1981) *Focussed Enumeration: the Development of a Method for Sampling Ethnic Minority Groups*, Policy Studies Institute/SCPR, London.

Structured observational research in services for people with learning disabilities

Brown P, Scullion L (2010). 'Doing research' with Gypsy-Travellers in England: reflections on experience and practice, *Community Development Journal*, 45, 2, 169–185.

Chahal K (2004) *Experiencing Ethnicity: Discrimination and service provision. Foundations: Analysis informing change*, Joseph Rowntree Foundation, York.

Chattoo S, Ahmad WIU (2008) The moral economy of selfhood and caring: negotiating boundaries of personal care as embodied moral practice, *Sociology of Health and Illness*, 30, 4, 550–564.

Confederation of Indian Organizations (1987) *Double Bind: to be disabled and Asian*, CIO, London.

Craig G, Adamson S, Ali N, Demsash F (2010) *Mapping rapidly changing minority ethnic populations: a case study of York*, Joseph Rowntree Foundation, York.

Craig G, Dornan P, Bradshaw J (2006) *Pensioner Poverty*, National Audit Office, London.

Culley L, Hudson, N, Rapport F (2007) Using focus groups with minority ethnic communities: researching infertility in British South Asian communities, *Qualitative Health Research*, 17, 1, 102–112.

Edwards R, Alexander C (2010) Researching with peer / community researchers: ambivalences and tensions, in Williams M, Vogt P, *Handbook of Methodological Innovations*, Sage, London.

Elam G, Fenton KA (2003) Researching sensitive issues and ethnicity: lessons from sexual health, *Ethnicity and Health*, 8, 1, 15–27.

Ellison GTH (2005) 'Population profiling' and public health risk: when and how should we use race/ethnicity? *Critical Public Health*, 15, 1, 65–74.

Esterhuizen L (2004) *Doing Case Studies for the Refugee Sector: A DIY Handbook for Agencies and Practitioners*, ICAR, London.

Fanshawe S, Sriskandarajah D (2010) *You can't put me in a box*, IPPR, London.

Fontes LA (1997) 'Conducting ethical cross-cultural research on family violence.' in Kantor GK, Jasinski JL (eds) *Out of the Darkness: Contemporary research perspectives on family violence*, Thousand Oaks, Sage.

GLAD, Greater London Action on Disability (1991) *Race and Disability: A dialogue for action - Conference Report*, GLAD, London.

Gonzalez S, Fayaz M, Nadeem A, Molla E, Leung A (2008) *Are Black and Minority Ethnic communities in Worcestershire appropriately supported by, and well-informed about, the health system in relation to mental health services?* Worcester, Age Concern Herefordshire and Worcestershire, <http://its-services.org.uk/silo/files/2008-community-engagement-interaction-worcestershire.pdf>

Structured observational research in services for people with learning disabilities

Grewal I, Ritchie J (2006) Ethnic and language matching of the researcher and the research group during design, fieldwork and analysis, in Nazroo, J (ed.) *Health and Social Research in Multiethnic Societies*, Routledge, Abingdon.

Gunaratnam Y (2001) 'We mustn't judge people ... but': staff dilemmas in dealing with racial harassment amongst hospice service users, *Sociology of Health and Illness*, 23, 1, 65–84.

Hanley B (2005) *Research as empowerment? Report of a series of seminars organised by the Toronto Group*, Joseph Rowntree Foundation, York.

Hills J (chair) (2009) *Inequality in the UK, Report of the National Panel on Inequality*, HMSO, London.

Horowitz CR, Brenner BL, Lachapelle S, Amara D, Arniella G (2009) Effective recruitment of minority populations through community-led strategies, *American Journal of Preventative Medicine*, 37, 6, S195–S200.

Hussain-Gambles M (2003) Ethnic minority under-representation in clinical trials: Whose responsibility is it anyway?, *Journal of Health Organization and Management* 17, 2, 138–143.

Jayaweera H, Hockley CA, Redshaw ME, Quigley MA (2007) *Demographic and socio-economic characteristics of ethnic minority mothers in England: Millenium Cohort Study*, Centre for Longitudinal Studies, London.

Johnson CE, Ali SA, Shipp, MP-L. (2009). Building community-based participatory research partnerships with a Somali refugee community, *American Journal of Preventative Medicine*, 37, 6, S230–S236.

Kalathil J (2008) *Dancing to our own tunes: reassessing black and minority ethnic mental health service user involvement*, Survivor Research, Sutton.

Kalra VS (2006) Ethnography as politics: A critical review of British studies of racialized minorities, *Ethnic and Racial Studies*, 29, 3, 452–470.

Katbamna S, Matthews R (2007) *Ageing & Ethnicity in England: A Demographic Profile of BME Older People in England*, Age Concern England [now Age UK], London.

Lawrence V, Samsi K, Banerjee S, Morgan C, Murray J (2010) Threat to valued elements of life: the experience of dementia across three ethnic groups, *The Gerontologist*, 51, 1, 39–50.

Lewis H, Craig G, Adamson S, Wilkinson M (2009) *Refugees, asylum-seekers and migrants in Yorkshire and Humber, a review of research 2000–2009*, Yorkshire Forward, Leeds.

Lievesley N (2010) *The Future Ageing of the Ethnic Minority Population of England and Wales*.

Structured observational research in services for people with learning disabilities

Runnymede Trust and Centre for Policy on Ageing, London. Available from:  
[www.runnymedetrust.org/publications/147/32.html](http://www.runnymedetrust.org/publications/147/32.html)

Lloyd CE, Johnson MRD, Mughal S; Sturt J, Collins G, Roy T, Bibi R, Barnett AH (2008a) 'Securing recruitment and obtaining informed consent in minority ethnic groups in the UK' *BMC Health Services Research* 8, 68–76.

Lloyd CE, Sturt J, Johnson M, Mughal S, Collins G, Barnett AH (2008b) Development of alternative methods of data collection in South Asians with Type 2 diabetes, *Diabetic Medicine*, 25, 455–462.

Mallinson S, Popay J (2007) Describing depression: ethnicity and the use of somatic imagery in accounts of mental distress, *Sociology of Health & Illness*, 29, 6, 857–871.

Manthorpe J, Iliffe S, Moriarty J, Cornes M, Clough R, Bright L, Rapaport J, OPRSI (Older People Researching Social Issues) (2009) 'We are not blaming anyone, but if we don't know about amenities, we cannot seek them out': black and minority older people's views on the quality of local health and personal social services in England', *Ageing & Society*, 29, 1, 93–113.

Manthorpe J, Moriarty J, Stevens M, Sharif N, Hussein S (2010) *Supporting black and minority ethnic older people's mental wellbeing: accounts of social care practice*, Social Care Institute for Excellence, London.

Manthorpe J, Bowes A (2010) Age ethnicity and equalities: policy and practice messages from recent studies of elder abuse in the UK. *Social Policy and Society* 9, 2, 255–26

McLean CA, Campbell CM (2003) Locating research informants in a multi-ethnic community: ethnic identities, social networks and recruitment methods, *Ethnicity and Health* 8, 1, 41–61.

McManus S, Erens, B, Bajekal M (2006) 'Conducting surveys among ethnic minority groups in Britain.' in J Nazroo (ed.) *Health and Social Research in Multiethnic Societies*, Routledge, Abingdon.

Mir G, Tovey P (2003) Asian carers' experiences of medical and social care: the case of cerebral palsy, *British Journal of Social Work*, 33, 4, 465–479.

Moriarty J, Sharif N, Robinson J (2011) *Black and Minority Ethnic People with Dementia and their Access to Support and Services*, SCIE Research Briefing 35, Social Care Institute for Excellence, London.

Nazroo J with Berthoud R, Erens B, Karlsen S, Purdon S (2005) *A Longitudinal Survey of Ethnic Minority People: Focus and Design* (summary), ESRC and ONS, London.

Nazroo JE, Falaschetti E, Pierce M, Primatesta P (2009) Ethnic inequalities in access to and outcomes of healthcare: analysis of the Health Survey for England, *Journal of Epidemiology and Community Health*, 63, 1022–1027.

Structured observational research in services for people with learning disabilities

NBCWN (National Black Carers and Workers Network) (2008) *Beyond We Care Too: Putting Black Carers in the Picture*, NBCWN, London.

Newbigging K, Lowe J (2005) *Direct Payments and Mental Health*, Joseph Rowntree Foundation, York.

Newbigging K, McKeown M, Hunkins-Hutchinson EA, French B with Habte-Mariam Z, Coleman-Hill L, Mullings D, Stephens A, Holt K (2007) *Mtetezi: Developing mental health advocacy with African and Caribbean men*, Social Care Institute for Excellence, London.

Oakley A (2006) Ethnicity and research evaluating health interventions: Issues of science and ethics, in Nazroo J (ed.) *Health and Social Research in Multiethnic Societies*, Routledge, Abingdon.

Papadopoulos I (2006) Culturally competent research: a model for its development, in Nazroo J (ed.) *Health and Social Research in Multiethnic Societies*, Routledge, Abingdon.

Parekh B (2006) *Rethinking Multiculturalism: Cultural Diversity and Political Theory*, Palgrave Macmillan, Basingstoke.

Phillimore J, Goodson L, Hennessy D, Ergun E (2008) *Making a Difference: empowering Birmingham's migrant community organisations*, Joseph Rowntree Foundation, York.

Plewis I with Calderwood L, Hawkes D, Hughes G, Joshi H. (2004) *The Millennium Cohort Study: Technical report on sampling*, Third Edition, Centre for Longitudinal Studies, London.

Praat A, Barker M, Craig G, Atkin K (2005) *Disability and Ethnicity: Black and minority ethnic groups with sensory disabilities in the labour market: a literature review*, Social Policy Working Papers, University of Hull.

Poudrier J, Mac-Lean RT (2009) 'We've fallen into the cracks': Aboriginal women's experiences with breast cancer through photovoice, *Nursing Enquiry*, 16, 4, 306–317.

Rai-Atkins A, with Jama AA, Wright N, Scott V, Perring C, Craig G, Katbamna S (2002) *Best Practice in Mental Health: Advocacy for African, Caribbean and South Asian communities*, Joseph Rowntree Foundation, York.

Rai D, Withey J (2006) *Newham Household Panel Survey (NHPS). Wave 4 report: poverty, employment, health, housing, quality of life, social capital, young people*, London Borough of Newham.

Roberts K and Harris J (2002) *Disabled People in Refugee and Asylum Seeking Communities*, Policy Press, Bristol.

Ruhs M, Anderson B, Rogaly B, Spencer S (2006) *Changing Status, Changing Lives? Methods, participants and lessons learnt*, ESRC Centre on Migration, Policy and Society (COMPAS), University of Oxford.

Structured observational research in services for people with learning disabilities

Salway S, Allmark P, Barley R, Higginbottom G, Gerrish K, Ellison GTH (2009a) Social research for a multiethnic population: do the research ethics and standards guidelines of UK Learned Societies address this challenge?, *Twenty-First Century Society* [now *Contemporary Social Science*], 4, 1, 53–81

Salway S, Allmark P, Barley R, Higginbottom G, Gerrish K, Ellison G (2009b), Researching ethnic inequalities, *Social Research Update*, 58, 1-4, University of Surrey, Guildford.

Salway S, Platt L, Chowbey P, Harriss K, Bayliss E (2007). *Long-Term Ill Health, Poverty and Ethnicity*, Joseph Rowntree Foundation, York.

Salway S, Barley R, Allmark P, Gerrish K, Higginbottom G, Ellison G (2011) *Ethnic Diversity and Inequality: ethical and scientific rigour in social research*, Joseph Rowntree Foundation, York. <http://www.jrf.org.uk/publications/ethnic-diversity-social-research>

Scott S, Craig G, Geddes A (2012) *The Experience of Forced Labour*, Joseph Rowntree Foundation, York (forthcoming).

Sharma S, Reimer-Kirkham S, Cochrane M (2009) Practicing the awareness of embodiment in qualitative health research: methodological reflections, *Qualitative Health Research*, 19, 11, 1642–1650.

Smith P, Pickering K, Williams J, Hay R (2010) *The Efficacy of Focused Enumeration*, [http://www.ipsos-mori.com/Assets/Docs/Publications/The\\_Efficacy\\_of\\_Focused\\_Enumeration.PDF](http://www.ipsos-mori.com/Assets/Docs/Publications/The_Efficacy_of_Focused_Enumeration.PDF)

Taylor C (1994) *Multiculturalism: Examining the Politics of Recognition*, Princeton University Press, Princeton.

Temple B, Moran R (eds) (2006) *Doing Research with Refugees: Issues and Guidelines*, The Policy Press, Bristol.

Vernon A (2002) *User-Defined Outcomes of Community Care for Asian Disabled People*, Policy Press/Joseph Rowntree Foundation, Bristol.

Wang C, Burris MA (1997) Photovoice: concept, methodology and use for participatory needs assessment, *Health and Behaviour*, 24, 369–387.



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**Appendix: web-based resources**

**Social Care Institute for Excellence**

<http://www.scie.org.uk/publications/signpostinginfo.asp>

'Signposting' summaries for resources which contain ethnic minority content.

**The King's Fund**

<http://www.kingsfund.org.uk>

Searchable database including substantial research content, reviews and reading lists on ethnic minorities in social care.

**Joseph Rowntree Foundation**

<http://www.jrf.org.uk>

Searchable database of reports with a strong focus on ethnic minorities and several specific browsable categories relating to social care.

**Equality Foundation**

<http://www.raceequalityfoundation.org.uk>

Training and research on race equality in social support and social care, with a strong focus on housing. Also has a specialist site focused on race equality in health:

<http://www.better-health.org.uk/index.htm>, and publishes a series of excellent briefing papers, each offering an overview of key issues on health, housing and social care.

**Ethnic Diversity in UK Social Research & Public Policy Research**

<http://research.shu.ac.uk/ethics-ethnicity>

Project outputs including presentations, articles and seminar summaries.

**Ethnicity Training Network**

<http://www.etn.leeds.ac.uk/index.htm>

NHS funded centre based at the University of Leeds. Site includes events, courses and resources.

**Information Centre About Asylum and Refugees**

<http://www.icar.org.uk>

Includes *refdata*, a catalogue of datasets relating to refugees and asylum seekers, and research guidance.

**Equality and Human Rights Commission**

<http://www.equalityhumanrights.com/>

Legal briefings, guidance on the Equality Act and other legislation, and inquiry findings.

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### Health for Asylum Seekers and Refugees Portal

<http://www.harpweb.org.uk/index.php>

Guidance on medical and social issues facing asylum seekers and refugees aimed at health professionals.

### NHS Evidence – ethnicity and health

<http://www.library.nhs.uk/ethnicity/>

Guide to online resources on health care and needs for migrant and minority ethnic groups, including some material on social care.

## Appendix: Journals

The most relevant research-oriented journals for discussions of the issues raised here are *Diversity in Health and Care* (Radcliffe), [http://www.radcliffe-oxford.com/journals/J26\\_Diversity\\_in\\_Health\\_and\\_Care/default.htm](http://www.radcliffe-oxford.com/journals/J26_Diversity_in_Health_and_Care/default.htm) and

*Ethnicity and Health* (Routledge) <http://www.tandf.co.uk/journals/carfax/13557858.html>

A more recent journal is *Ethnicity and Inequalities in Health and Social Care* (Pavilion Press), <http://www.pierprofessional.com/eihscflyer/index.html>